

Brief Descriptions of Learning Activities for Medical Education

The six chapters of Part II provide examples of medical education activities that have been developed and co-taught with patient- and family-advisors. An interested reader should find enough detail in any one chapter to try a similar activity in another medical school or residency program. Reading these examples may also stimulate new ideas for activities tailored to the educational needs of another group of learners or another curricular setting. The activities employ a variety of educational formats, including workshops, small-group discussions, lectures, home visits and independent research projects. While each chapter describes a very different activity or set of activities, they all provide goals, objectives, some thoughts about the curricular context of the activities, a description of one or more educational activities, a discussion about the role and contribution of patient- and family-advisors, and some thoughts about preparation that the advisors need to participate in teaching these activities. A brief summary of each chapter appears below.

Chapter 5. Teaching Advocacy with Patients and Families

One important aim of medical education is to convey the knowledge and skills needed to advocate for patients and families in complex healthcare systems. When teaching about advocacy, patient- and family-advisors who live with complicated or long-term health conditions bring knowledge about needed resources and appreciation for a physician's role in linking patients and families with these resources. Teaching about advocacy may begin with an encounter with a standardized patient who presents a complex medical and social situation. In such an encounter, the learner's task is not to do a medical assessment, but to build an understanding of the goals and wishes of the patient and discuss healthcare and community resources that can help the patient achieve those goals. This may be followed by small group discussions with parent- or patient-advisors that have experience with a serious medical challenge such as a stroke, an organ transplant, or cancer. The advisors work

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intensively with a small group of learners to complete activities that emphasize ways to plan collaboratively for good care within the context of a patient's life and goals.

Chapter 6. Home Visits

Home visits bring medical students or residents into a person's home and community, where the patient- or family-advisors may be more comfortable and able to communicate more openly about their lives and their experiences with health care. Home visits also enable students and residents to see the environments in which people live their lives and implement healthcare recommendations. Understanding the context of a patient's life provides a necessary foundation for a physician to make optimal medical decisions with patients and to advocate for patients.

Home visits can also address other purposes. Patients may be more frank in discussing their views about medical care. The visit may serve to convey to the resident or student the resilience of people in the face of challenging health conditions and it may build an understanding of the variety of resources and interventions that help people live their lives well.

Chapter 7. Medical Ethics with Parent Collaborators

In education about medical ethics, small group discussions with patients or parents put a human face on ethical decision-making in critical healthcare settings. In one approach to these discussions, parents who have faced very serious medical decisions for their infants or young children share the stories of their child's medical crises and describe decisions they have made. They then offer the learners an opportunity to ask probing questions about the families' experiences and the parents' struggles with difficult decisions and ethical quandaries. Parents can explain how physicians have supported them in making decisions and discuss the learners' future approach to supporting parents in similarly difficult medical circumstances. Parents also provide a perspective on long-term rewards and challenges for children and families after an intense or critical medical experience.

Chapter 8. Parent Presentations about Developmental Disabilities

Occasional lecture presentations by parent- or patient-advisors can add a human dimension to didactic material. The presentations described here address developmental disabilities with a slide show and question-and-answer session by parents. The parents translate diagnostic criteria into challenges and experiences from their children's lives, while students or residents ask questions of the parents as they seek to understand the realities of life with a disability. Parents share pictures of their children and provide stories about their children at home, in the community, and at school. Learners acquire information about developmental disabilities and hear about the implications of special needs in the lives of children and families, along with parents' reflections about how physicians can help address needs.

Chapter 9. Interactive Learning with Parent Co-Teachers

Case-based interactive learning sessions provide an opportunity to involve parents as co-teachers to address focused topics. One-hour sessions begin with a short didactic presentation, followed by small groups in which learners explore a specific topic with parents. Parents share their children's stories and speak from their own experience. They also generalize from their experience to broader concepts that apply to many children and families, helping learners see how insights from a specific family's experience apply to other patients and families. One child and family's experience becomes a case example, which when coupled with interaction in small groups provides contextual learning about the topic. Parents also provide individualized feedback to a small group of learners. Three examples of case-based, interactive learning sessions include the following: an introduction to the pediatric interview that forms part of a course on the medical interview, a session to explore communication challenges during a Pediatric Clerkship, and an introduction to developmental pediatrics with a focus on early intervention for children with special needs.

Chapter 10. Research with Patients and Families

A research project can be constructed as an elective for a medical student or a resident with a patient- and family-advisory group as the major resource. A student or resident interested in patient/physician relationships and communication or patient and family perspectives on medical care can formulate a research question that involves partnering with parents of children with special needs or adults with chronic conditions. Research projects can address widely diverse topics such as the following:

- The role of music in enhancing language development in children with autism.
- How to write an understandable and respectful consent form for parents for a study of serous otitis.
- How to write a guide for parents of children newly diagnosed with autism.
- Patients' advice for medical students and physicians about doing a helpful medical interview.
- How to present news of a cardiac murmur to parents.

Medical students may carry their initial research interest into their residencies and residents into their fellowships and careers.